

February 22, 2013

Dear Senator Gerratana, Representative Johnson and members of the Public Health Committee,

I am writing in support of Senate Bill 360, an act concerning pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections. My profound thanks to Senator Kevin Witkos, Representative John Hampton and Representative Geoff Luxenberg for the introduction of this legislation.

In the Spring of 2011, my son was diagnosed with PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections.) Much like my son's autism diagnosis, received in 2003, this PANDAS diagnosis came with an element of relief. At least my husband and I knew something of what was happening to our child and had some sort of explanation for what can only be described as the months of hell prior.

Living with autism, our family has grown accustomed to challenging behaviors at times, but in general my son Jack is a happy kid who loves to laugh, read and be with his family. He was never self injurious or aggressive towards anyone. He met developmental milestones like walking, toileting and sleeping through the night at relatively appropriate times. He excelled in school, particularly math and science. After infancy, he was never chronically ill. Despite autism, he was making phenomenal academic and social strides.

Until the Fall of 2010, when at the age of 9, Jack began a spiral of behavioral regression. He bit himself and others, enough to break the skin. He began wetting his bed again. He could not sleep through the night and woke for the day at 3 a.m. for months on end. His body was laced with rashes and he was plagued by so much self stimulatory behavior that he cried and cried with frustration, and then lashed out with aggressive punching and hitting. He could not remain in his typical classroom due to screaming outbursts at classmates and teachers. He could not tolerate being touched or hugged. He had outbreak after outbreak of strep throat, ear infections, sinus infections and fever. He could not remember how to do math, the math he had known how to do since he was five. Our pediatrician suggested medication after medication for autism related anxiety, of no avail. He suggested tonsilectomies and adnoid removal. Our school had no idea how to provide appropriate services. This was not the child anyone knew. This was not our child. This was a child who was being tortured within his own body every second of every day. To watch your child in this agony...helplessly...day after day is devastating. Pure Hell.

After much researching, networking, pushing and then REALLY pushing my pediatrician, we came upon reknowned immunologist, Dr. Denis Bouboulis and received our diagnosis. The following months of intense intervention with heavy antibiotics and homeopathic remedies eventually brought our child back. Jack remains on a prophylactic

dose of antibiotics now and we remain vigilant in limiting his exposure to strep, as these debilitating behaviors can sometimes return when exposure occurs.

In writing this testimony I cannot help but think back on the fast and furious tailspin that was our life during the time Jack went undiagnosed. The nightmare our whole family was living, including Jack's younger brothers. No one knew what to do. No one.

As an autism mom, I am quite used to having to educate and advocate at almost every turn for my child. PANDAS adds another layer to the complexity of my ability to do that. The community in general, as so many have commented, still can only think of PANDAS as a cute and cuddly zoo animal. The medical community in general does not lend it's existence much credence. Educators try to fruitlessly treat it with behavioral interventions.

For these reasons, I wholeheartedly support SB360 and its effort to provide outreach to the medical community, and beyond, about PANDAS.

I am happy to speak further should you require.

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Mother to Jack &
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